

## FACT SHEET

**When a Newborn Doesn't Pass the Hearing Screening:**

# **How Medical and Other Health Professionals Can Help Increase the Number of Infants Who Return for a Follow-up Evaluation**

Each year, approximately 12,000 babies are born with hearing loss in the United States. If hearing loss is discovered during the “critical period” for children to develop their speech and language skills—from birth to the first two to three years of life—they will have a much better chance of keeping up with their peers in learning language and speech skills. If they miss this critical period of development, they can fall far behind their peers in these areas. This delay, in turn, can affect a child’s ability to learn and interact socially.

Medical and allied health professionals across the United States have played a vital role in helping identify hearing loss during a child’s first months of life. As of July 2003, mandatory newborn hearing screening programs have been implemented in 38 states and the District of Columbia. As a result, roughly 86.5 percent of all infants are now screened for hearing loss, usually before they leave the hospital.

But screening is only the beginning of a successful path for infants who are deaf or hard-of-hearing. Newborns who don’t pass the screening should receive an audiometric evaluation and medical diagnosis before the child is three months of age. An audiologist is a health professional who conducts a series of tests to determine whether the child has a hearing problem and, if so, the type and severity of that problem. An otolaryngologist, or ear, nose, and throat doctor, will try to find out the reason behind a hearing loss and offer treatment options. These professionals will help direct parents or other caregivers to resources that can help them. (See the NIDCD fact sheet *Milestones in Your Child’s Speech and Language Development*.)

In the year 2000, only approximately half of the children who were referred for a follow-up examination were brought back for one. Parents of deaf or hard-of-hearing children in this group were much less likely to take advantage of the many resources that could give their children the best start possible and the best long-term outcome.

## **Why don't some parents return for a follow-up examination?**

A working group of the National Institute on Deafness and Other Communication Disorders identified several important factors regarding why some parents do not bring their child back for a follow-up examination. They concluded that the number of children who return for the follow-up examination could be improved if:

- Parents fully understood their child's screening results,
- Parents fully understood the importance of the diagnostic evaluation, and
- Parents were provided with necessary contact and resource information.

A few of the most commonly cited reasons for the low response rate are included below, along with communication initiatives that you, the medical professional, can implement to help improve the outcome.

*“With so many people involved in the process, it's difficult to be sure that the information is being relayed to parents.”—Charles*

- **Take responsibility**

This is particularly true if the child is sent to the neonatal intensive care unit (NICU). A NICU physician may not see the parents again until several days after the child is born, if ever. A person on the medical team should be responsible for understanding and being able to interpret and carefully explain to parents the infant's screening results. It is extremely important that this individual be able to explain to parents why a follow-up examination is needed. Outdated wisdom that “parents can check back in a year to see if there is a change” is shortchanging children who could benefit from early intervention services.

- **Develop a protocol**

Develop a protocol to ensure that all parents receive the same information during their baby's birth and hospital stay. The more consistent the procedure and message, the less likely that a family will leave the hospital without understanding the next steps they need to take and why. With shortened maternity stays, this protocol becomes even more critical.

*“There's no system in place to make sure that parents make and keep the follow-up appointment.”—Jocelyn*

- **Obtain the family's contact information**

Medical staff should check in with families after they leave the hospital to make sure they've taken their child to the diagnostic evaluation. To facilitate ongoing communication, ask families to complete a discharge questionnaire before they leave the hospital, including names, addresses, phone numbers, e-mail addresses, and any other useful contact information.

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- **Connect the child with a ‘medical home’**

As soon as a child is born, the family should be linked to a “medical home,” a term that, according to the American Academy of Pediatrics (AAP), refers to healthcare services that are coordinated, comprehensive, family-centered, and accessible, among other things. This centralized system makes it easier for medical staff to track a child’s medical visits, recognizing immediately from his or her records whether the follow-up examination has been completed. To learn more about the “medical home” concept, and how your role and the role of your staff would be affected, contact the AAP for possible training sessions in your state or region at [www.aap.org](http://www.aap.org).

- **Give office staff a lead role**

Office staff should help families navigate the healthcare system, which can be quite complicated for individuals who are unfamiliar with it or who have difficulty reading or understanding the English language. By providing easy-to-read checklists and contact information, volunteering to schedule the follow-up appointment, and checking in with families to make sure that the appointment has been kept, office staff can help provide the needed push to ensure that this important task is completed.

- **Offer broad-based institutional support**

When feasible, hospitals should develop a support structure that will help medical staff better perform their duties in this area. This might include:

- modeling the hearing screening and diagnostic evaluation after an already-established program, such as metabolic screening;
- integrating health information systems to ensure that each child’s records are readily available to all health professionals who need to access them; and
- coordinating the billing for hospital services with the receipt of all follow-up information.

*“There aren’t enough people or resources available to handle the screening and follow-up process.”—Miguel*

- **Cross-train staff**

In communities where resources or staff are lacking, hospitals could cross-train medical staff to perform screening and follow-up testing. With adequate supervision, technicians, paramedics and emergency medical personnel, volunteers, nurses (as well as nurse aides and assistants), lab technicians, and respiratory therapists can be trained to perform some of these tasks on an as-needed basis.

*“Parents don’t seem to understand the importance of the follow-up exam.”—Deborah*

- **Communicate accurately and carefully**

Parents need to be told plainly what their child’s screening results mean and why the follow-up examination is important. A flier or brochure, no matter how well written or designed, is not enough on its own: some parents may have difficulty reading it or

comprehending certain medical terms. Or they may toss it away without a glance. Assign the “communicator” role to a designated staff person, making sure that parents are encouraged to ask questions. To further guarantee their understanding, have parents explain in their own words the next step they need to take and why. If you’d like to give parents something in writing at the end of the sit-down meeting, the NIDCD fact sheet *What to Do if Your Baby’s Screening Reveals a Possible Hearing Problem* is available at the NIDCD Web site. See the Web address listed below.

- **Be sensitive to cultural and other differences**

Your message can be filtered or even skewed by a number of factors, such as a parent’s culture, ethnicity, race, and socioeconomic background. For example, concepts that are generally accepted by some groups may be entirely unfamiliar to others. When communicating with parents, pay attention to these differences, and avoid using terms or expressions that may be easily misinterpreted.

- **Explain how a hearing loss can hamper a child’s speech and language development**

Parents may not understand how a possible hearing loss might impact their life and the life of their child. Furthermore, they may mistakenly think that little can be done about it. For these reasons, it’s important to explain to parents how detecting a hearing loss early—before their child reaches three months of age—and introducing intervention by the time the child reaches six months of age can keep a child on the right track developmentally and ensure he or she achieves the appropriate milestones for successful school, work, and social experiences.

*“Returning for an appointment can be burdensome for some parents.”—Tia*

- **Use incentives, when appropriate, such as travel vouchers**

Transportation can present a problem for families, particularly those who live in rural areas or who use public transportation. If possible, provide incentives such as free travel vouchers to help defray the cost. Another suggestion is to offer an instant photograph of the child at birth, at the follow-up examination, and during intervention.

- **Perform the follow-up exam while parents are still at the hospital**

If an audiologist is on site, explore ways for infants who don’t pass the screening to receive a definitive auditory brainstem response (ABR) test before they leave the hospital. The ABR involves attaching electrodes to the head and recording electrical activity in the brain when a sound is generated.

- **Combine follow-up exam with well-baby check-ups**

Families who are unable to transport themselves to a medical facility may rely on home health nursing to conduct their well-baby check-ups. In these cases, an audiologist may be able to provide follow-up testing during one of the home visits.

*“Parents sometimes feel powerless and ‘out of the loop’ regarding their child’s health-care.”—Gavin*

- **Involve the entire family in the screening**

When possible, make the infant’s hearing screening an interactive experience for the family by checking several family members’ hearing at the same time. The more involved

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a family is, the greater their appreciation for the importance of the screening and follow-up evaluation.

- **Equip parents with information for decision-making**

When a child is found to be deaf or hard-of-hearing, parents and other family members must make a difficult and highly personal decision regarding how the child will communicate. For example, the child may use a combination of oral and auditory skills together with assistive or augmentative devices, such as hearing aids, cochlear implants, FM transmitters, and other technologies. Or the child may learn American Sign Language (ASL), speechreading, cued speech, or a combination of oral and manual measures. Medical and other health professionals can provide information that enables parents to explore communication options, research findings, and informal support mechanisms before making their choice. (See the NIDCD fact sheets *Communication Considerations for Parents of Deaf and Hard-of-Hearing Children*, *Silence Isn't Always Golden*, and *Milestones in Your Child's Speech and Language Development*.)

- **Use a family-centered approach**

During office or home visits, physicians should involve the child's family. In this way, families are trained to serve as the first line of care for their infants and are empowered to make sure that their child receives the best health treatment possible.

### What all parents need to know before they leave the hospital:

- ☐ The time frame in which parents need to respond:
  - ☐ **By 1 month:** Parents should have their babies screened by 1 month of age.
  - ☐ **By 3 months:** If the baby does not pass the screening, parents should take him or her to a follow-up evaluation by 3 months age.
  - ☐ **By 6 months:** If hearing loss is confirmed, parents should have their child enrolled in some type of intervention by 6 months of age.
- ☐ Speech and language developmental milestones and how hearing loss affects their child's ability to achieve these milestones. (See the NIDCD fact sheet *Milestones in Your Child's Speech and Language Development*.)
- ☐ The results of their child's hearing screening and what the results mean. (See the NIDCD fact sheet *Has Your Baby's Hearing Been Screened?*)
- ☐ **For parents of children who do not pass the screening:** Why a follow-up examination is necessary and how to go about getting one. (See the NIDCD fact sheet *What to Do if Your Baby's Screening Reveals a Possible Hearing Problem*.)
- ☐ Contact information for making the follow-up appointment for a diagnostic evaluation.
 

This might include a list of certified audiologists and otolaryngologists in the area along with addresses and phone numbers. Office staff may also volunteer to make the appointment for the parents.
- ☐ State, federal, and nonprofit resources available to them if their child should have a hearing problem (see list below).

■ For more information, contact:

NIDCD Information Clearinghouse  
1 Communication Avenue  
Bethesda, MD 20892-3456

1-800-241-1044  
1-800-241-1055 (TTY)  
E-mail: [nidcdinfo@nidcd.nih.gov](mailto:nidcdinfo@nidcd.nih.gov)  
Internet: [www.nidcd.nih.gov](http://www.nidcd.nih.gov)

The NIDCD Information Clearinghouse  
is a service of the  
National Institute on Deafness and Other  
Communication Disorders

## Free publications from the NIDCD

The following titles are just a sample of those available for free on the NIDCD Web site. Spanish versions are also available for each of the titles below. Hard copies can be ordered from the NIDCD Clearinghouse and reproduced free of charge.

- Communication Considerations for Parents of Deaf and Hard-of-Hearing Children  
[www.nidcd.nih.gov/health/hearing/commopt.asp](http://www.nidcd.nih.gov/health/hearing/commopt.asp)
- Milestones in Your Child's Speech and Language Development  
[www.nidcd.nih.gov/health/voice/thebasics\\_speechandlanguage.asp](http://www.nidcd.nih.gov/health/voice/thebasics_speechandlanguage.asp)
- Silence Isn't Always Golden  
[www.nidcd.nih.gov/health/hearing/silence.asp](http://www.nidcd.nih.gov/health/hearing/silence.asp)
- What to Do if Your Baby's Screening Reveals a Possible Hearing Problem  
[www.nidcd.nih.gov/health/hearing/baby\\_screening.asp](http://www.nidcd.nih.gov/health/hearing/baby_screening.asp)
- Has Your Baby's Hearing Been Screened?  
[www.nidcd.nih.gov/health/hearing/screened.asp](http://www.nidcd.nih.gov/health/hearing/screened.asp)

The NIDCD Clearinghouse has additional information on speech and language development, communication options, cochlear implants, hearing aids, American Sign Language, and other topics covered in this fact sheet. There are several ways to contact us:

1 Communication Avenue

Bethesda, MD 20892-3456

Toll-free: (800) 241-1044

Toll-free TTY: (800) 241-1055

E-mail: [nidcdinfo@nidcd.nih.gov](mailto:nidcdinfo@nidcd.nih.gov)

Contact the NIDCD Clearinghouse to be added to our mailing list. You'll receive the biannual newsletter *Inside* and a copy of our national directory of resources.

## Resources for parents of a child with hearing loss

### Educational Services

**Families and Advocates Partners for Education (FAPE)** is a partnership funded by the U.S. Department of Education that strives to improve the educational outcomes for children with disabilities. It informs parents, administrators, service providers, and policymakers about the Individuals with Disabilities Education Act (IDEA).

PACER Center

8161 Normandale Boulevard, Minneapolis, MN 55437-1044

Voice: (952) 838-9000

TTY: (952) 838-0190

Fax: (952) 838-0199

E-mail: [fape@fape.org](mailto:fape@fape.org)

Internet: [www.fape.org](http://www.fape.org)

**Head Start Information and Publication Center** supports the Head Start community and other organizations working in the interest of children and families by providing information products and services; conference and meeting support; publication distribution; and marketing and outreach efforts.



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**U.S. Department of Health and Human Services**

1133 15th Street, N.W., Suite 450

Washington, DC 20005

Voice: (202) 737-1030

Toll-free: (866) 763-6481

Fax: (202) 737-1151

E-mail: [askus@headstartinfo.org](mailto:askus@headstartinfo.org)

Internet: [www.headstartinfo.org](http://www.headstartinfo.org)

**Office of Special Education Programs (OSEP)** is dedicated to improving results for infants, toddlers, children, and youth with disabilities, ages birth through 21, by providing leadership and financial support to assist states and local districts.

Office of Special Education and

Rehabilitative Services

U.S. Department of Education

400 Maryland Ave., S.W.

Washington, DC 20202

Voice: (202) 205-5507

Internet: [www.ed.gov/offices/OSERS/OSEP/index.html](http://www.ed.gov/offices/OSERS/OSEP/index.html)

**Support Services**

**Beginnings for Parents of Children Who Are Deaf or Hard of Hearing, Inc.** provides impartial information on communication options, placement, and educational programs to parents of children who are deaf or hard-of-hearing.

P.O. Box 17646

Raleigh, NC 27619

Voice/TTY: (919) 850-2746

Fax: (919) 850-2804

E-mail: [beginnings@beginningssvcs.com](mailto:beginnings@beginningssvcs.com)

Internet: [www.beginningssvcs.com](http://www.beginningssvcs.com)

**Center for Children's Policy, Practice and Research** is an interdisciplinary center that helps protect the health and welfare of children by providing clinical assessments and legal testimony, conducting research, offering advice and consultation, influencing public policy, and disseminating information.

4200 Pine Street, 3rd Floor, Philadelphia, PA 19104

Voice: (215) 573-5442

Fax: (215) 573-2791

E-mail: [ccppr@ssw.upenn.edu](mailto:ccppr@ssw.upenn.edu)

Internet: [www.ssw.upenn.edu/CCPPR](http://www.ssw.upenn.edu/CCPPR)

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Internet: [www.nidcd.nih.gov](http://www.nidcd.nih.gov)

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Communication Disorders

**National Association of the Deaf (NAD)** is the nation's largest consumer organization safeguarding the accessibility and civil rights of 28 million deaf and hard-of-hearing Americans in education, employment, health care, and telecommunications. NAD focuses on grassroots advocacy and empowerment, captioned media, deafness-related information and publications, legal assistance, policy development and research, public awareness, certification of interpreters, and youth leadership development.

814 Thayer Avenue  
Silver Spring, MD 20910-4500  
Voice: (301) 587-1788  
TTY: (301) 587-1789  
Fax: (301) 587-1791  
E-mail: [nadinfo@nad.org](mailto:nadinfo@nad.org)  
Internet: [www.nad.org](http://www.nad.org)

### **General Information and Referral Services**

**American Academy of Audiology (AAA)** is a professional membership organization of individuals dedicated to providing high-quality hearing care to the public.

8300 Greensboro Drive, Suite 750  
McLean, VA 22102  
Voice/TTY: (703) 790-8466  
Toll Free: (800) 222-2336  
Fax: (703) 790-8631  
Internet: [www.audiology.org](http://www.audiology.org)

**American Academy of Otolaryngology—Head and Neck Surgery (AAO-HNS)** is a non-profit association that strives to unite, serve, and represent the interests of ear, nose, and throat specialists and their patients to the public, government, other medical specialists, and related organizations.

One Prince Street  
Alexandria, VA 22314  
Voice: (703) 836-4444  
TTY: (703) 519-1585  
Fax: (703) 683-5100  
E-mail: [webmaster@entnet.org](mailto:webmaster@entnet.org)  
Internet: [www.entnet.org](http://www.entnet.org)

**American Academy of Pediatrics (AAP)** is a professional membership organization of pediatricians dedicated to the health, safety, and well-being of all infants, children, adolescents, and young adults.

141 Northwest Point Boulevard, Elk Grove Village, IL 60007-1098  
Voice: (847) 434-4000  
Fax: (847) 434-8000  
Internet: [www.aap.org](http://www.aap.org) (general); [www.aap.org/advocacy/shrinersorder.htm](http://www.aap.org/advocacy/shrinersorder.htm) (medical home training)



## F A C T S H E E T

**American Speech-Language-Hearing Association (ASHA)** promotes the interests of and the highest quality services for professionals in audiology, speech-language pathology, and speech and hearing science, and advocates for people with communication disabilities.

10801 Rockville Pike

Rockville, MD 20852

Voice: (301) 897-3279

Fax: (301) 897-7355

Toll-free: (800) 638-8255

E-mail: [actioncenter@asha.org](mailto:actioncenter@asha.org)

Internet: [www.asha.org](http://www.asha.org)

**AT&T HealthLine** is a health-information hotline sponsored by the Centers for Disease Control and Prevention and the National Center on Birth Defects and Developmental Disabilities.

Toll-free: (888) 232-6789

**Laurent Clerc National Deaf Education Center** at Gallaudet University responds to inquiries about a diverse range of topics related to deaf and hard-of-hearing children from infancy to age 21.

KDES PAS-6, 800 Florida Avenue, N.E.

Washington, DC 20002-3695

Voice: (202) 651-5051

TTY: (202) 651-5052

Fax: (202) 651-5054

E-mail: [clearinghouse.infotogo@gallaudet.edu](mailto:clearinghouse.infotogo@gallaudet.edu)

Internet: [clerccenter.gallaudet.edu](http://clerccenter.gallaudet.edu)

**National Information Center for Children and Youth with Disabilities (NICHCY)** is a national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals. NICHCY's special focus is children and youth (birth to age 22).

P.O. Box 1492, Washington, DC 20013-1492

Voice/TTY: (202) 884-8200

Toll-free: (800) 695-0285

Hours: 9:30 a.m. – 6:30 p.m., Eastern Time

Fax: (202) 884-8441

E-mail: [nichcy@aed.org](mailto:nichcy@aed.org)

Internet: [www.nichcy.org](http://www.nichcy.org)

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1 Communication Avenue  
Bethesda, MD 20892-3456

1-800-241-1044  
1-800-241-1055 (TTY)  
E-mail: [nidcdinfo@nidcd.nih.gov](mailto:nidcdinfo@nidcd.nih.gov)  
Internet: [www.nidcd.nih.gov](http://www.nidcd.nih.gov)

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is a service of the  
National Institute on Deafness and Other  
Communication Disorders

## Communication Options

**Alexander Graham Bell Association for the Deaf and Hard of Hearing (A.G. Bell)** is a membership-based information center on hearing loss, emphasizing the use of technology, speech, speechreading, residual hearing, and written and spoken language.

3417 Volta Place, N.W.

Washington, DC 20007

Voice: (800) HEAR-KID or (202) 337-5220

TTY: (202) 337-5220

Fax: (202) 337-8314

E-mail: [info@aol.com](mailto:info@aol.com)

Internet: [www.agbell.org](http://www.agbell.org)

**American Society for Deaf Children (ASDC)** is a national organization of families and professionals committed to educating, empowering, and supporting parents and families of children who are deaf or hard-of-hearing. The ASDC helps families find meaningful communication options, particularly through the competent use of sign language, in their home, school, and community.

P.O. Box 3355

Gettysburg, PA 17325

Voice/TTY: (717) 334-7922

Toll-free: (800) 942-ASDC

E-mail: [ASDC1@aol.com](mailto:ASDC1@aol.com)

Internet: [www.deafchildren.org](http://www.deafchildren.org)

**National Cued Speech Association (NCSA)** promotes the effective use of cued speech for communication, language acquisition in more than 50 languages, and literacy.

23970 Hermitage Road

Shaker Heights, OH 44122

Toll-free Voice/TTY: (800) 459-3529

Fax: (216) 360-0359

E-mail: [cuedspdisc@aol.com](mailto:cuedspdisc@aol.com)

Internet: [www.cuedspeech.org](http://www.cuedspeech.org)

## Clinical Studies

**Boys Town National Research Hospital (BTNRH)** conducts research into and treatment of childhood deafness and communication disorders. Areas of study include neurobiological studies of hearing; hereditary communication disorders; and clinical, educational, and behavioral studies of human communication.

555 North 30th Street, Omaha, NE 68131

Voice: (402) 498-6511

TTY: (402) 498-6543

Toll-free: (800) 282-6657

Fax: (402) 498-6755

E-mail: [moeller@boystown.org](mailto:moeller@boystown.org)

Internet: <http://www.boystown.org/btnrh>

